Governor's Working Group on Mental Retardation Services

State of Maine

Final Report of Working Group

[Date of submission]

Submitted to:

John Baldacci, Governor
State of Maine

Jack Nicholas, Commissioner
State of Maine Department of Health and Human Services

Governor's Working Group on Mental Retardation Services

State of Maine

Summary of the Group's Work and Draft Recommendations

The Charge: The primary charge of the work group was stated by the Governor in his appointment letter dated March 4, 2004:

> *"The working group will be charged with reviewing and ultimately making recommendations by January 31, 2005 to the Commissioner and me on current and prospective policies, practices, and services affecting and available to citizens with mental retardation. The group will examine the factors that drive the escalation of the costs in the mental retardation system and propose strategies to reduce system-related costs without depreciating the quality of services and supports."*

The working group has discussed policies, practices and services in the system and has made numerous comments in the body of the report. The majority of its work has focused on the examination of cost drivers and the identification of strategies to reduce system-related costs without depreciating the quality of services and supports.

Working Group Membership: The Working Group of 18 members (and 5 guests in frequent or regular attendance) has broad representation from all constituencies in the mental retardation system, including but not limited to consumers, parents, legislators, providers, departmental administrators, and advocates.

Basic Principles: Before it examined costs in the system, the Group identified certain basic principles to guide its work. The Group recognizes that each person served by the mental retardation system is unique. Services and supports must always strive to maximize each person's independence, self-sufficiency, full and integrated inclusion in the fabric of life in the community in which the person lives, and capacity for self-advocacy. *(Please see Section II, for a full presentation and description of the Guiding Principles used for the Working Group and proposed for the system of services and supports.)*

The Process and Methodology: The group met 12 times between March 26 and November 18, 2004. A significant amount of work gaining information and perspectives was performed outside of the group meetings by individual members in concert with constituency groups and interested community members. The process used by the working group was the following:

- Agree on the charge of the working group – in order to define the focus, activities, goals and timelines;
- Identify and define essential components or "guiding principles" to be used as a philosophical and practical context to guide the work of the committee and the redesign or refinement of services;
    - Initial exercise by working group
    - Follow-up additions and editing
    - Integrate work group principles with position statements from other groups
    - Ongoing review of guiding principles for task coverage and relevancy

- Establish a draft work plan to guide the work of the committee.
- Gather and organize data about costs and cost drivers, assessment and rating models, current and innovative services, system management approaches, and other areas related to the charge of the working group. Review the following:
    - System cost information and comparative data from other states
    - Information from parallel system development and/or reorganization committees, grant projects and stakeholder groups
    - Information from constituency groups of committee members (e.g., Maine Association of Community Service Providers, Maine Parent Federation)
    - Other information as needed
- Review and analyze data and compare views of different stakeholders represented on working group;
- Ensure open opportunities exist to solicit and receive input, feedback and guidance from the broad constituencies of working group members as well as the general public; and
- Synthesize information and points of view and develop prioritized recommendations to be presented in a summary of the group's work. *(Presented in draft form at this time.)*

The current draft document presents the guiding principles and a conceptual discussion of cost drivers and potential strategies to address those cost drivers. The working group relied on a conceptual approach because of the inability of the current financial system to compile, summarize and report current costs in a valid and reliable fashion. Because of the qualitative validation methodologies used to summarize data and draw conclusions, the members of the working group do not believe this limits either the validity of the cost drivers or the utility of the strategies that have been offered.

The strategies identified do not represent a consensus view of committee members. The membership wanted to ensure that further discussion and study of strategies that may hold promise were not limited simply because the strategies were not endorsed unanimously by the group. The reader must therefore understand that all strategies identified in the report are not "endorsed" by the group members or larger constituency groups they may represent. Individual strategies have been included in the report to provide the reader with a full portrayal of all options that some members of the group believed were worthy of consideration. This point of view was taken to avoid a common outcome of groups such as this where a large number of opinions and options are merged to a few select recommendations that an entire group can agree on. What is often the result of approaches such as this is a list of featureless recommendations that can be dismissed by the reader and have only limited impact on the system.

The cost drivers and strategies also do not always represent discrete concepts or options. Overlap exists between and among cost drivers and selected strategies are proposed for multiple, related cost drivers. The working group believed that a wide view of the problems and their potential solutions would be a productive way to approach the task.

No separate emphasis or study was invested in the very small number of large budget consumer programs (typically, individual budgets greater than $200,000). A study was recently carried out by DHHS staff in coordination with the Special Court Master of the Community Consent Decree. It has been reported to this committee that the vast majority of programs requiring the large budgets have been reviewed and validated by this group. The unique needs experienced by this small group of consumers results in specialized programs. While it is important for the system to be aware of and continue to closely monitor these programs, the working group members believe this is not a source of significant savings across the system – only in a very few instances that may be directly related to misdiagnosis of medical or psychological disorders.

Recommendations: What follows in this summary is a set of broad recommendations. They are distilled from many hours of discussion and debate. The system of support for Maine's citizens with mental retardation is complex, and the reader should be cautioned that the Work Group's full, as opposed to summarized, recommendations include nuance and detail that for the sake of brevity are not included in this summary. In ad-

dition, not all of the actions recommended by the group can be implemented at once. The Group has therefore identified short-term strategies (implemented within a period of six month and exerting an immediate impact on the system), short and long term strategies (implementation should begin in the first six months with anticipated impact in one to three years), and long terms strategies (implementation over a longer term with long-term and/or ongoing impact in the system.)

Short Term

1. The state must create a clearly defined, standardized rate setting process based upon valid assessments of consumer need and choice that allows for individualization. As envisioned, service definitions that would form the basis for the rates would take into account geographic differences in the state; living and service arrangements for the specific consumers being supported; the developmental level, behavioral and medical needs of the person served; and increases in the costs of living and doing business. (Please see Sections 1b, 1c, 1d, and 10b in the full report for additional information.)

2. Variations of the "waiver" or Home and Community Benefits program under MaineCare must be developed, so that the waiver can be "capitated" and "self-directed". This will utilize the primary federal funding source for Maine's citizens with mental retardation more effectively, and enable the waiver to fund consumers who require single services needs such as employment and other community inclusion services. The Working Group would like to recognize the progress that has been made already in the development of these new waiver programs and would urge the Department of Health and Human Services to continue moving quickly and diligently on this effort. (Please see Sections 2a, and 8 in the full report for additional information.)

Short and Long Term

1. Person Centered Planning (PCP) is a highly individualized and effective planning system. In order to promote and reinforce creativity on the part of PCP team members, the primary determinant for success of any consumer's PCP must shift to outcome indicators that measure the quality of life and success of integration into the community for that person. (Please see Sections 1a and 15 in the full report for additional information.)

2. A standing group of service providers, state officials, consumers and family members should review licensing and fire marshal standards, training mandates, standardized contracts and contracting processes, and related regulatory requirements to identify inconsistencies and overlap, and suggest changes that would minimize the cost of service delivery while still retaining health and safety protections and accountability. PNMI (Private non-medical institution) regulations should be revised to allow for increased flexibility in funding, budgeting, and auditing requirements. Budget development, billing, fiscal monitoring and other administrative processes should be studied to increase efficiencies across the system. (Please see Sections 4c, 9, 11, 13, 17 and 18 in the full report for additional information.)

3. The system must study the feasibility of engaging in alternative, creative service delivery approaches. The system should minimize center-based day and vocational services, and seek community-based employment and community inclusion options. For young adults transitioning from school to adult services, post-secondary education or training opportunities, employment and other community inclusion services must be the primary expectations. Residential options must utilize as much as possible, co-location of consumers allowing for the sharing of staff, consumer guided congregate apartment models, and ISO's (Independent Service Options). Most importantly, the system must provide incentives to providers who devise creative methods of providing natural residential, vocational and community inclusion supports. (Please see Sections 3a, 3b, 4, 28 and 29 in the full report for additional information.)

4. Undiagnosed or misdiagnosed physical or psychological disorders can result in behavioral excesses and challenges that compromise the ability of the system to support a consumer successfully in the community and can result in unnecessary costs. The system must develop and reinforce the ability to promote and deliver high quality diagnostic and health care interventions to all consumers. Maine also

should collaborate with other New England states to develop clinical assessment and intervention services in specialized instances (e.g., non-adjudicated offenders), utilizing the region's exceptional professional resources and expertise. (Please see Sections 5 and 6 in the full report for additional information.)

5. A home or place of residence is a life long need. Maine should encourage home ownership by consumers, including but not limited to owner-resident congregate living options. Consumers should be able to stay in their own home and participate fully in making decisions about their services and who provides those services. (Please see Sections 2 and 23 in the full report for additional information.)

Long Term

1. High turnover of staff increases training, recruitment, and administrative costs. Wages, benefits and annual cost of living adjustments for Maine's direct support personnel must be made at least consistent with other jobs in Maine that require similar training and skill. Apprenticeship in the profession and partnerships with Maine's colleges and technical schools are necessary to encourage people to choose this field as a career, and to foster professionalism in the workforce. (Please see Sections 12 and 25 in the full report for additional information.)

2. All Maine citizens with mental retardation who meet MR/DD eligibility criteria should receive services parallel to the services described in the "Pineland" Community Consent Decree. There should not be multiple tiers of service based on the historical accident of whether a person was once a resident of Pineland. (Please see Section 22 in the full report for additional information.)

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State of Maine

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SECTION I

A. Task of the working group

1. Description of the Governor's charge

In March, 2004, Governor Baldacci invited an array of stakeholders to participate in a working group to study the complex issues that confront Maine citizens with mental retardation. He wrote that our state deserves to be proud of the excellent support system that has been developed and indicated that his administration is devoted to its continuation.

Governor Baldacci charged the working group with the following:

"The working group will be charged with reviewing and ultimately making recommendations by January 31, 2005 to the Commissioner and me on current and prospective policies, practices, and services affecting and available to citizens with mental retardation. The group will examine the factors that drive the escalation of the costs in the mental retardation system and propose strategies to reduce system-related costs without depreciating the quality of services and supports. During the process, I ask that the working group cooperate and consult with the Court Master who oversees the Community Consent Decree."

2. Primary tasks and goals of the working group

During the initial meetings, the working group established the following tasks and goals as its primary focus:

- *Identify guiding principles for the services, the system and the working group;*
- *Gather and organize data about costs and cost drivers, assessment and rating models, current and innovative services, system management approaches, and other areas related to the charge of the working group;*
- *Review and analyze data and compare views of different stakeholders represented on working group;*
- *Ensure open opportunities exist to solicit and receive input, feedback and guidance from the broad constituencies of working group members as well as the general public; and*
- *Synthesize information and points of view and develop conclusions, recommendations and final report.*

Since its first meeting, it has been the intention of the working group members to identify cost drivers and potential intervention strategies in such a way that recommended actions will improve the overall quality of services and supports to consumers, both in the short run and in the long run.

It is important to note that no separate emphasis or study was invested in the small number of large budget consumer programs (individual budgets greater than $200,000). A study was recently carried out by DHHS staff in coordination with the Special Court Master of the Community Consent Decree. It has been reported to this committee that the vast majority of programs requiring the large budgets have been reviewed and validated by this group. The unique needs experienced by this small group of consumers require specialized programs. While it is important for the system to be aware of and continue to closely monitor these programs, the working group members believe this is not a source of significant savings for the system. Savings that may occur for this group result from the very few instances directly related to misdiagnosis of medical or psychological disorders.

B. Working group membership

Co-chairs:

Steven Leclair
Community Partners, Inc.
Biddeford, ME

Geoff Green
BDS (DHHS)
Augusta, ME

Members:

Laura Antranigian
Speaking Up for US - Maine
Portland, ME

Kevin Baack
Goodwill Industries
Portland, ME

Rep. Margaret Craven
Maine State Legislature
Lewiston, ME

Sandi Dunham
Maine Parent Federation
S. Gardiner, ME

Debbie Elliott
Parent and Advocate
Portland, Maine

Patrick Ende
Office of the Governor
Augusta, ME

Jane Gallivan
BDS (DHHS)
Augusta, ME

Debbie Gilmer
Maine Support Network /
Western Maine Partnership, UMF
Farmington, ME

Marie Hodgdon
BDS (DHHS)
Augusta, ME

Matthew Hunter
Parent and Advocate
Chelsea, ME

Charlene Kinnelly
Uplift, Inc.
Gardiner, ME

Carol Lanouette
Speaking Up for Us - Maine
S. Gardiner, ME

Rep. Arthur Lerman
Maine State Legislature
Augusta, ME

Peter Rice
Disability Rights Center
Augusta, ME

Steve Richards
Consumer Advisory Board
Presque Isle, ME

Christine Zukas-Lessard
DHS/BMS (DHHS)
Augusta, ME

Guests in frequent or regular attendance at working group meetings

Richard Estabrook
Office of Advocacy
Augusta, ME

Andrew Roth-Wells
Maine Developmental Disabilities Council
Augusta, ME

Lisa Collins
Maine Developmental Disabilities Council
Augusta, ME

David Goddu
BDS (DHHS)
Augusta, ME

Craig Anderson
Goodwill Industries
Portland, ME

C. Methodology

The following describes the methodology used to identify the guiding principles of the group, work plan, cost drivers, potential intervention strategies, and system recommendations. This represents a significant amount of work over a period of eight months. Much of the work gaining information and exploring perspectives was performed outside of the group meetings by individual member in concert with constituency and stakeholder groups and other interested community members.

Assumptions: The work of the group has been guided, in part, by a number of practical assumptions. It is important to note that some assumptions listed below are not held by all members of the group but did influence the group's discussions and summary of recommendations.

1) The system of services and supports for Maine citizens with mental retardation and other developmental disabilities is an extremely successful example of individualized, person-centered planning to maximize independence, community inclusion and the capacity for self-advocacy. While excellent services are delivered in the system, it has the capacity for improvement and increased cost efficiency.

2) The State of Maine and the United States of America are experiencing a financial crisis, particularly with regard to the support for and delivery of critical human services. The working group makes the assumption that while the level of crisis will abate over time, the financial well-being of human service delivery may be compromised for the foreseeable future. This assumption must be acknowledged in all aspects of service delivery planning.

3) A critical aspect of identifying cost drivers is the availability of valid, reliable and specific information about costs (e.g., cost breakdowns across service types, regions, providers, and service coordinators; specific DHHS administrative expenses; and specific information about consumer needs on an individual and/or aggregate basis). The working group learned that the department is not able to produce data at this level of specificity. The more specific the financial and service data, the more suspect its reliability and validity become. The working group would therefore have to identify cost drivers and strategies without having specific financial information.

4) Members of the working group believed it possible to rely on a structured, qualitative methodology to identify specific cost drivers at a conceptual level; validate them through discussion, agreement and community input; and establish a series of potential strategies that may address them. This conceptual exercise offered the potential for addressing problems that had not been openly discussed before because the lack of specific financial information forced (and allowed) the committee to look at all possible cost drivers and methods to address them rather than only those currently tracked in the system.

Process: The group met 12 times between March 26 and November 18, 2004.

Meeting Dates:		
	March 26, 2004	August 19, 2004
	April 9, 2004	September 2, 2004
	April 29, 2004	September 27, 2004
	June 10, 2004	October 14, 2004
	July 1, 2004	November 4, 2004
	July 22, 2004	November 18, 2004

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1. Agree on the charge of the working group – in order to define the focus, activities, goals and timelines;
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    - Follow-up additions and editing
    - Integrate work group principles with philosophical underpinning and position statements from other groups
    - Ongoing review of guiding principles for task coverage and relevancy
3. Establish a draft work plan to guide the work of the committee.
4. Gather and organize data about costs and cost drivers, assessment and rating models, current and innovative services, system management approaches, and other areas related to the charge of the working group. Review the following:
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    - Information from parallel system development and/or reorganization committees, grant projects and stakeholder groups
    - Information from constituency groups of committee members (e.g., Maine Association of Community Service Providers, Maine Parent Federation)
    - Other information as needed
5. Review and analyze data and compare views of different stakeholders represented on working group;
6. Ensure open opportunities exist to solicit and receive input, feedback and guidance from the broad constituencies of working group members as well as the general public;
7. Develop a draft document that is reviewed by external editors to minimize professional and trade jargon and ensure the highest level of readability prior to public review and comment; and
8. Synthesize information and points of view and develop prioritized recommendations to be presented in a summary of the group's work. ***(Presented in draft form at this time and <u>not</u> prioritized.)***

The current draft document presents the guiding principles and a conceptual discussion of cost drivers and potential strategies to address those cost drivers. The working group relied on a conceptual approach because of the inability of the current financial system to compile, summarize and report current costs in a valid and reliable fashion. Because of the qualitative validation methodologies used to summarize data and draw conclusions, a majority of the members of the working group do not believe this limits either the validity of the cost drivers or the utility of the strategies that have been offered.

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D. Glossary of terms used in report

APS: *Adult Protective Services*

BDS: *Department of Behavioral and Developmental Services* (title no longer in se – now a component of DHHS)

CMS: *U.S. Centers for Medicare and Medicaid Services* (formerly known as HCFA)

Community-based living: Living in one's community of choice with the supports, services and programs available and accessible that enable each person to live as independently as possible.

Community inclusion: The act of welcoming and engaging people with disabilities in as active members of the community including: 1) recognizing and assuring an individual's right to access; 2) providing adaptations that allow individuals to participate and benefit from services; and 3) Creating a supportive atmosphere where social acceptance, positive interactions and friendships can develop.

Congregate living: Independent apartments with some degree of shared living and other supportive services to promote maximal independence among residents with functional impairment who do not require constant supervision

Consumer: A recipient of services, the term "self-advocate" is also used.

Day habilitation: Often referred to as "day hab". Very specific, strict definitions for day habilitation activities are included in various regulations. For the purpose of this document, day habilitation simply refers to either facility-based or community-based services to promote or enhance personal, social and independent living skill development.

Developmental disability: A severe chronic disabling condition that is: 1) attributable to a mental or physical impairment or combination of mental and physical impairments; 2) is manifested before the individual attains age 22; 3) is likely to continue indefinitely; 4) results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; economic self-sufficiency; and 5) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated

DHS: *Department of Human Services* (title no longer in use)

DHHS: *Department of Health and Human Services*

EIS: *Electronic Information System*

FSD: *Free Standing Day Habilitation*

G&A: General and Administrative costs

Guardian: Person(s) or agency with ongoing legal responsibility for ensuring the care of an individual, appointed pursuant to 18-A MRSA, Article 5, Part 3.

ICF: *Intermediate Care Facility:* a comprehensive residential service that focuses on an active treatment approach established and delivered by an interdisciplinary team. Also ICF/MR – an intermediate care facility specifically designed to meet the needs of people with mental retardation.

In-home supports: Providing services and supports in a consumer's home in order to promote the ability to promote and/or maintain maximum levels of independence.

ISO: ***Independent Service Option:*** a particular residential services model offered to clients of DHHS by agencies authorized by DHHS to provide such services. The model is flexible in order to best meet the needs of the individual served. Services typically take place in the home in which the Direct Support Provider lives with the person served. Services can range from minimal support from one Direct Support Provider to extensive support for medical, behavioral and/or activities of daily living needs by both a Direct Support Provider and scheduled shift staff employed by the Agency.

Medicaid Waiver: *Home and Community-based Waiver for Persons with Mental Retardation:* A MaineCare benefit which includes certain habilitation, transportation, respite care, adaptive aids, communication aids, crisis intervention environmental modification, personal support, residential training, and supported employment services. These services allow a MaineCare member to reside in the least restrictive setting and is a waiver to the ICF regulations.

Mental retardation: As defined at 34-B MRSA § 5001, a condition of significantly subaverage intellectual functioning resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period.

PCP: *Person Centered Plan:* The document in which the needs and desires of the person are articulated and identified based upon an assessment of the person served and habilitative goals and objectives and the resources and methods necessary to implement them are written.

Person Centered Planning: a process of determining, with the person, the person's family and guardian, and other providers, what services and resources are necessary to meet the identified needs and desires of the person and how they might be most appropriately delivered. The plan is designed to maintain current service delivery and to resolve gaps in services so that comprehensive care is attained.

PNMI: *Private Non-Medical Institution:* a particular type of residential group living arrangement that generally serves six or more residents.

Provider: The entity responsible for service provision, including paid staff or any other person receiving any form of compensation for service provision in the MR/DD system.

Residential: Support in a residential environment, ranging from independent living options to 24 hour support in a group environment.

Self-advocacy: A national movement of people with disabilities speaking and advocating for themselves. A *self-advocate* is sometimes used as a term to identify a consumer of services in the system.

Sheltered employment: Employment assistance and support for persons who are not viewed as capable of working in a competitive employment setting in their local community. *Sheltered transitional employment* programs are intended to provide support to persons in a segregated setting so they will be able to acquire the skills necessary in subsequent competitive employment. *Extended sheltered employment* is a long-term or permanent placement in a work setting that will allow a person to use existing abilities to earn wages in a segregated setting.

Supported employment: Support that helps people with severe disabilities find and maintain competitive work in an integrated setting where they might not otherwise be able to do so. The supports can include job coaching, transportation, assistive technology, specialized job training and individually tailored supervision.

Ticket to Work: A new, voluntary program for SSDI (Social Security Disability Insurance or SSI (Supplemental Security Income) recipients. The goal of the program is to help beneficiaries obtain and maintain employment and earn enough money so they will not need Social Security case benefits.

Governor's Working Group on Mental Retardation Services

Guiding Principles, Cost Drivers and Potential Intervention Strategies

SECTION II. GUIDING PRINCIPLES

A. The system of services and supports should reflect each person's uniqueness and individuality.	Each individual has a unique personal background and set of strengths, needs and desires. This uniqueness must be respected and addressed through an individualized, person-centered planning process that is characterized by informed choice, equal opportunity, control over one's life, health and safety.
B. Services and supports to persons with developmental disabilities should maximize independence, community inclusion and the capacity for self-advocacy.	Services and supports should be designed so the level of both personal independence and community inclusion experienced by each consumer is maximized. This should be assessed on a regular basis in order to promote continuous improvement in services and to offer the opportunity for self-directed growth and decision-making among consumers.
C. The system of services should be consistent, fair and flexible.	Services and programs should be designed so they are future oriented, responsive and flexible so the system can respond to the needs of entrants as well as the evolving needs of ongoing participants.
D. The system of services should be cost effective and efficient.	The system of services should be cost effective on an individual and programmatic basis. A rate setting methodology should be in place that is: 1) characterized by clarity, consistency and fairness; 2) designed to meet consumer strengths and needs; and 3) responds to legitimate costs of doing business in an efficient manner. Rate setting and budgeting should be based on requirements that are communicated clearly and openly and operate consistently across people, programs, providers, and regional offices. Congruence should exist between justifiable costs associated with an individual consumer's program and the funding available for that program.
E. The DHHS organizational structure should promote the monitoring, regulating, evaluating and funding of services and support to persons with developmental disabilities.	The Department of Health and Human Services should have a structure, decision-making process, communication flow and regulatory policies that will promote the continuous improvement of services and supports to persons with mental retardation in an accountable, person-centered and fiscally sound manner. This includes the establishment and refinement of regulations with direct value to the delivery of services and the continuous review of the value of all unfunded mandates.
F. The DHHS system should be highly realistic and practical in the decision making process associated with programs and services, acknowledging the human and physical asset value of current systems, the practical realities of the process of change and the cost of service delivery.	The delivery of services and supports for Maine residents with mental retardation is planned, organized and carried out at the local level through and in collaboration with a network of private providers. Any change process must take into consideration the impact upon the human and physical assets and obligations of that service system and be designed and implemented in such a way that the integrity of services and supports to consumers is not compromised due to limited service choices.

Section III. Cost Drivers, Potential Intervention Strategies and Guiding Principle Supporting Strategy

III. A. Service and Program Design Drivers and Strategies

Cost drivers	Potential Intervention Strategies
1. The Person Centered Planning (PCP) process as it is currently defined is a highly individualized and effective method to assess and document individual needs and establish a suitable plan of action. The methods used in this planning process are sometimes applied inconsistently and the integrity of the true PCP process is vulnerable to competing and conflicting self-interests among state case workers (ISC's), guardians and providers. • **A "disconnect" occurs between a consumer's identified and documented needs and the services available, potentially resulting in unnecessary and costly service provision.** Funding capacity and approaches should fit service needs evident in the system. This is particularly related to the current Medicaid Waiver. "Replacement" services are sometimes provided because the funding mechanism one qualifies for doesn't allow the system to provide the service that is needed. • **Another "disconnect" sometimes occurs with a discrepancy between identified and documented needs / "wants" of the consumer, and the needs/"wants" of the ISC, parent/guardian and/or provider.** When an ISC, a parent / guardian, a provider or another team member imposes a personal or professional point of view (that person's "want") on the planning process, the team-based planning process moves quickly away from the "PCP" model and becomes prescriptive, reflecting the point of view of that team member – not the needs of the consumer. This approach threatens the viability of the plan,	1.a. Support and maintain the integrity of the assessment, planning, implementation and evaluation process by defining consumer strengths, needs and goals and focusing program accountability on the outcomes of services. *Shifting to an outcome-based model would address any perceptions that the system does not focus on assisting consumers to reach a high level of success. Progress toward goals would be the focus of system assessment and would be tracked and documented. This would also promote and reinforce creativity on the part of providers and other members of the team to identify and implement novel, innovative and less costly support approaches. A focus on process without an emphasis on outcomes reinforces linear thinking and limits possibilities.* *In order to achieve this, the system would need to make several changes in program regulations to minimize the required focus on process and increase focus on outcomes. See #15 below for additional comments and requirements.* 1.b. Needs assessment that may be included in the PCP process and/or any standardized rate setting process should involve providers, consumers and guardians/family members to ensure all relevant information is included in the analysis. *This assessment would require an independent review of results to maintain objectivity and standardization. A completely independent assessment (performed by an external agent), while often reliable (consistent from one person to another or from one time to another) often lacks validity, particularly in complex human service assessment tasks.* 1.c. Create a standardized rate setting process – not limited to an elementary system of "published rates." *This would be based on a valid assessment of consumer need and choice and result in a clearly defined system of establishing rates. The system should allow for individualization through the establishment of service definitions that are specific and varying enough to reflect the unique aspects of: geographical influences, living and service arrangements, behavioral and medical needs, and the developmental level of the service recipients. This would result in a standardized approach with a wide array of standardized rates which would allow for differences in service needs between and among consumers. The process should be applied consistently across all consumers, providers, ISC's and regions.*

and limits the capability of the team to develop and implement an effective individualized, person-centered plan. It is always more costly. • **The system lacks clear, well-communicated definitions of services. This makes it impossible to create consistent expectations for process or outcome and severely limits the ability of the system to create standardized rates or a standardized rate setting process.** While definitions exist on paper, they are often ambiguous and arbitrary in actual practice. What is day hab? Supported employment? What services are billable, allowable, or not allowable? Clear definitions of concepts and services are essential if we want to develop a standardized rate setting process and be able to monitor and evaluate the system in any reliable way. Current ambiguities create inconsistencies that result in higher system costs.	1.d. Providers, state officials and other stakeholders should work together to develop a standardized set of definitions for each service. *These definitions should be unambiguous, clearly communicated and form the basis for the rate setting methodology.* 1.e. Streamline regulatory requirements and minimize non-value-added regulations and inefficient standard operating procedures.
2. A "disconnect" exists between current services and needs of some consumers (due, in part, to restricted funding mechanisms). This forces people into more expensive service options simply because they are available, not necessarily because these options meet a specific consumer's needs. The current Medicaid waiver and Intermediate Care Facility (ICF) regulations are inadequate and severely limited in their ability to meet the support needs of consumers. This is particularly true for persons who need a specific service that is inconsistent with the regulations or the funding mechanism available to them. (E.g., a consumer lives in the family home and requires professional support only in an employment setting. Free standing day habilitation (FSD) may be the only federal funding source available – other than State grant money – and it is contrary to regulations to pay for work supports with FSD money.)	2.a. A new waiver is needed for greater flexibility to meet different and/or changing levels of need, particularly with consumers who require single services such as limited day or vocational support. *The State of Maine is working at this time to develop alternative waivers for submission to the U.S. Centers for Medicare and Medicaid Services. We believe this is an extremely important step which will allow a more strategic use of funding from this federal program. It will allow the system to meet individual needs more effectively and in a much more cost effective manner.* *This may require more than one additional waiver, depending on the needs identified in the system on an ongoing basis. Additional waiver(s) should allow the State of Maine to align its funding priorities and capabilities.* *The ability and willingness of the State of Maine to appropriate the seed money required to take advantage of any new waiver is a potential obstacle. This working group believes that an additional appropriation to fund this waiver would allow consumers to be served much more efficiently, thereby creating both short-term and long-term cost savings in the system.*
3. Maine's services rely on a large number of somewhat traditional, parallel services. This limitation minimizes choice and maintains the current cost structure.	*Particular successes have been achieved using models that have been successful in other areas of the country or in other human service industries and adapted for use in this environment.* 3. Study the feasibility of using models that have resulted in success in other environments or with other populations and apply them as a method to support consumers in Maine. Examples of such models include:

	a. <u>Residential</u>: (1) "Owner-resident" type congregate living options with availability of individualized supports (e.g., similar to Highland Green in Topsham); (2) Consumer guided congregate living options with availability of individualized supports (rental, group ownership, provider ownership); (3) Revise/adapt regulations in the PNMI (Private non-medical institution) program to allow increased flexibility in funding, budgeting and auditing requirements, thereby increasing the viability of this option for providers and consumers; (4) ISO's and live-in residential arrangements; and (5) In-home supports – while they are a central component of many service options for children, they are not used as prominently among adults at this time. b. <u>Non-residential (not limited to residential)</u> (1) Self-determination as a core principle of service delivery, to the degree possible and appropriate; (2) Support entrepreneurial work ventures that provide integrated, paid work opportunities for consumer participants and adequate net revenue to self-sustain the business aspect of the venture; (3) Peer support programs offered both as a primary service and in support of more traditional service options; and (4) Invest in "transitional services" for people entering the adult system for the first time or in a different capacity (e.g., young adults transitioning from school, more mature adults transitioning from home into a community living program). This investment will minimize costs significantly over time.
4. The wide variety of needs presented by consumers requires the system to have multiple types of community-based programs available from which to choose. This results in costs associated with actively maintaining that variety. This requires funders and regulators to ensure systems are in place so all necessary programs are able to operate as efficiently and cost-effectively as possible. The following variables and factors are ***examples*** of the program options and choices currently available in the system: **<u>Residential choices and decisions</u>:** • Residential programs of various types and sizes (e.g., unli-	While the system acknowledges that some people who require 24-hour supports may benefit from smaller, unlicensed residential placements, it is possible for high quality services to be delivered in larger living arrangements if revisions in current licensing regulations would allow for more creative, less costly methods of delivering services. The following strategies could result in higher quality, less costly services in residential, day and vocational programs: 4.a. When programs are co-located in apartment houses, duplexes, or when they are in close physical proximity in another way, sharing of staff could be allowed (particularly during overnight hours) so staffing costs can be decreased. This may require the use of unobtrusive and inconspicuous monitoring technology to allow for rapid response in time of need and emergency. This would also require a change in licensing requirements associated with the expectations associated with 24 hour staffing. 4.b. Increase the use of consumer-guided congregate apartment models to extend the capacity of independent living options. A congregate living option would allow consumers with more com-

censed programs, licensed waiver homes, ICF's/MR, PNMI, etc.) • Individual Service Options (ISO's) and other live-in staffing residential arrangements • Dispersed and congregate apartment models for independent and semi-independent living programs • In-home and community-based support programs • Respite programs (respite for consumers, for live-in staff and ISO providers, and for families) • Staffing patterns designed to address all aspects of a PCP vs. staffing patterns designed to ensure basic support, health and safety needs **<u>Non-residential issues</u>** (not limited to residential): • Center-based vs. community-based day and vocational programs • One-to-one, small group service delivery vs. relying, in part, on natural supports in the community. • Current financial disincentives for delivering and/or organizing small group services • Liability and funding issues associated with the delivery of services that rely on natural supports • Staffing patterns designed to address all aspects of a PCP vs. staffing patterns designed to ensure basic support, health and safety needs	plex needs to live independently (often with a roommate) and minimize the cost of 24 hour staffing. 4.c. Revise/adapt regulations in the PNMI (Private non-medical institution) program to allow increased flexibility in funding, budgeting and auditing requirements, thereby increasing the viability of this option for providers and consumers. 4.d. Explore the potential for increased use of ISO's (Independent Service Option) and other types of live-in residential options <u>if stability can be achieved in terms of live-in staff and/or host family interest, commitment, and quality of service</u>. 4.e. Ensure that paid, productive work opportunities are available for consumers when that goal is included in the person centered plan and it has been determined that the consumer has the capability to engage successfully in such an activity. 4.f. For both day and vocational programs, minimize the use of center-based programming to avoid the costs associated with maintaining facilities and programs dependent on facilities. Openly acknowledge the support of community-based inclusion models based on natural supports and either individualized or group-based services in the community. This may not be a cost control in every instance over the short run, but considerable empirical evidence exists and *it has been generally accepted in the professional rehabilitation/habilitation fields (and reflected in the literature since the 1970's) that center-based services are more costly and result in less consumer success on most meaningful criteria.*
5. Chronic and severe physical health conditions which occur at any age (particularly toward the end of someone's life) can be cost drivers in the system. This is due, in part, to the lack of clear protocols to assess, plan, implement and evaluate program options associated with these events. This issue is often referred to as "aging in place", which is an unfortunate misnomer. It is important to understand the difference between "aging in place" (supporting consumers with medical conditions in their homes as they age) versus addressing intensive, long term medical needs of consumers. When a significant change in health status occurs, many aspects of the	5.a. Develop an appraisal process and tool(s) to assess the ongoing health care needs of a consumer facing a significant and/or long-term medical condition <u>as well as</u> the interaction between the medical condition, ongoing support needs (documented in the person-centered plan), and the skills and capacity of the current support setting to address the needs successfully. *(This process should include a consistent method to identify when the level of care required exceeds the capacity and skill of the current support setting and requires a referral to a more intensive setting, either temporarily or on a long-term basis.)* 5.b. Develop system-wide care protocols for meeting medical support needs that can be addressed in the in-home environment in order to provide guidelines for planning teams. 5.c. Develop direct support staff and nurse training modules for common medical conditions that

PCP may no longer be the center of attention. The focus of support may shift to medical, nursing and, possibly, end of life care. This type of change will affect a small number of people (quite consistent with the general population) – those who require a greater level of health care support due to a complex, chronic health care issue. Problems may be associated with the ability of the current residential situation (independent, with family, extended supports or 24 hour support) to satisfactorily address increasingly complex health care needs that result in the need for a more intensive level of support and/or care. Another facet of this issue is the need consumers have for timely access to high quality health care services if and when they experience an illness or injury. In this regard, their need is the same as any other citizen of Maine, complicated by limited accessibility to knowledgeable and experienced providers and limitations in funding.	will be available to providers, guardians, physicians and contracted nursing services. 5.d. Establish criteria which differentiate between situations that require a permanent (or long-standing) versus a time-limited change in domicile and support. 5.e. Ensure consumers have access to timely, high quality health care diagnostic and intervention services that are funded through either the MaineCare system or another source of health care coverage.
6. Significant costs are associated with the residential support of consumers who are "non-adjudicated offenders". A small group of consumers who are identified as perpetrators of violent acts are supported residentially in a highly individualized manner. While public and personal safety concerns have been addressed, the system's ability to assess and treat the underlying emotional, behavioral or physical disorders that may contribute to or exacerbate the problems have not been addressed successfully. This has resulted in very high cost programs with limited progress toward effective treatment outcomes. Another aspect of the challenge is the fact that the state is limited in its ability to develop a comprehensive approach and affect change because of the small number of consumers who are actually involved.	6.a. Maine should follow-through in collaboration with other New England states and participate in a multi-state compact to develop clinical assessment and intervention services. *This strategy would allow Maine to increase its ability and capacity to address the problem and share the costs with other states who are challenged by the same issue. This action is currently underway at the Department of Health and Human Services.* 6.b. The state should study and identify the feasibility of implementing alternative methods and use current technologies to ensure public safety and the safety of the consumer. *It may be possible to rely on technological advances to monitor the whereabouts and activities of a consumer and address the safety needs of that person and the public. This may include different types of audio, video and GSM resources as well as personal monitoring equipment that may be worn by the consumer. This would allow the program to minimize the use of staff who have a primary purpose of monitoring. It is important to realize, however, that this should not be used as a rationale to minimize staffing associated with desirable therapeutic interventions identified to address the primary problem areas. It may be most effective to contract with outside vendors who have expertise in this area to either conduct the monitoring function or provide the entire service.*
7. Unrealistic expectations of the level of support required to achieve stated outcomes and inconsistency associated with the identification of "preferred program models" are among the cost drivers in the system: • The manner in which the current system operationalizes individualization and personal choice in the service planning	7.a. Reinforce and reward creative methods of providing support that achieve successful outcomes in a cost efficient manner. Promote teams to be bold and "think outside of the box." 7.b. DHHS, providers, guardians and consumers should not limit themselves by identifying preferred program models. *The reinforcement and reward of creativity and calculated risk taking will allow the system to become more cost effective, while improving the quality of consumer support. This will result in a system that will find its own balance between quality service provision and budgetary reali-*

and implementation process is costly. **An individualized approach does not have to translate into a one-to-one service model.** Practical reality must be a cornerstone of the system in order to achieve fiscal responsibility. • What can often increase or exacerbate costs so they become less controlled are unrealistic or unreasonable expectations on the part of an ISC, a parent/guardian or a provider. On occasion, the system has been susceptible to a "flavor of the day" approach to program preference and funding. Results from research and demonstration projects and anecdotal information from projects in other areas (that may or may not be generalizeable or sustainable) often define new preferences. When this occurs and results in a preference change that takes hold for a period of years, the system redesigns itself (at considerable cost), aligns itself along a new path, until another "flavor" turns the heads of decision makers. This is not a phenomenon owned by either the State or providers – both have pushed agendas with enough fervor to influence the system.	*ties. The stipulations of the consent decree and external regulatory factors also must be built into the decision making process. Rely on an open market model with a contractual service approach and let the market define preferences.*
8. Due to funding regulations, the system is sometimes limited in its ability to provide day services (day habilitation, community inclusion, etc.) in a manner that is consistent with the needs of a large number of consumers. This forces consumers who wish to participate in meaningful activity to engage in services that may be more expensive, inconsistent with their needs, and don't result in successful outcomes.	8.a. Examine limiting formal day programming to consumers who have a defined and documented need and choice in the PCP, rather than including this service as a core element in every program simply because it is what is available. In some instances, the need for the available services is documented in order to fit what is available in the system. 8.b. A new waiver is needed that allows for greater flexibility to meet different and/or changing levels of need, particularly with consumers who require single services such as limited day or vocational programs. ***(See 2.a., above)***

III. B. System Design and Administrative Process Drivers and Strategies	
Cost Drivers	**Potential Intervention Strategies**
9. Residential licensing regulations Requirements related to training, certification, reporting, documentation, fire marshal, safety, and staffing expectations to meet licensing standards translate into costs. Selected regulations may be unnecessary to maintain safety, quality and accountability. When regulations or *their local interpretation* change, costs are added and are often not recognized in the budgeting process.	9. A comprehensive review of licensing standards and associated regulations is necessary to identify the relevance of current regulations and the potential for minimizing or revising regulations to lower costs (without threatening service quality or accountability). *Specifically, this would require a review of licensing regulations for all levels of Medicaid waiver homes, Children's residential licensing regulations, PNMI regulations, and ICF/MR regulations.*
10. Communication challenges between state and providers, consumers and guardians resulting in inconsistency, confusion and increased costs throughout the system: • The former DHS and BDS have a history of inconsistency in interactions with providers and in terms of their expectations of services and administrative processes; • The roles, responsibilities and internal communications of State central office vs. region and "program vs. finance" are often inconsistent and poorly defined in practice; • Considerable differences exist in the way regions operate. Varying messages are communicated to providers, consumers and guardians depending on where the message originates; and • Standard operating procedures used by individual ISC's working in the same office often vary widely. This inconsistency and confusion contributes to poor communication between the State offices and providers, consumers and guardians, resulting in unnecessary costs to the system.	10.a. Establish defined, communicated and consistently applied roles, responsibilities and standard operating procedures at DHHS (at all levels, across functions and between and among Central offices, regional offices and local offices). *If this is put into place successfully, it will go far to improve communication between the State and providers, guardians and consumers and will minimize a significant cost driver that currently exists due to the inconsistency and confusion.* 10.b. Define standardized operating procedures and rate setting methodologies which will guide the transformation of the PCP into a defined system of services. *The necessary individualized focus of the PCP process without an accompanying system of standardized procedures for rate setting may have contributed to significant confusion and increased costs. Reinforcing a standardized approach will allow the system to respond to individualized needs, within a consistent and accountable framework.*

11. Regulations and unfunded mandates Several regulations, legal mandates and institutionalized expectations have been put into place or have evolved over time that have contributed to costs: • Reportable events, APS investigations, training mandates, immunizations, accreditation requirements, standardized contracts and contracting processes, HIPAA and FMLA regulations all have added costs to the delivery of service. • If they are optional (not legally mandated) and do <u>not</u> result in a defined and measurable impact on the quality of services for consumers <u>or</u> directly support accountability and controls needed to operate the system – they should be eliminated or substantially revised to minimize associated costs. • If they are legally mandated or offer a necessary addition to the service structure, they must be acknowledged as a cost of doing business and built into G&A formulae.	11. Identify a standing group of service providers, state officials and primary/ secondary consumers to study existing and planned regulations, requirements and standards across all DHHS programs to accomplish the following: (1) Review all regulations, requirements and standards to identify their current relevance and utility and the potential for eliminating or revising regulations to minimize costs (without threatening service quality or accountability). (2) Review regulations, requirements and standards to identify inconsistencies and overlap across state government branches, departments and specific programs. Identify those regulations, requirements and standards that result in inconsistencies that can be eliminated or revised to improve the quality of support and minimize costs. A charge of this group would be to identify desirable changes that would require state statutory revisions and/or negotiation with federal agencies. *Particularly troublesome are measures that are put into place by one government branch, possibly to enhance their own revenue (e.g., criminal checks), that are required (but not funded) in another department's regulations. In these instances, a cost benefit analysis should be conducted to analyze the value of the regulation in view of the costs associated with it.*
12. Costs associated with professional and paraprofessional staff in the community-based system Staffing costs have consistently represented the greatest costs in the system, regardless of the type of service. Adequate wages to attract and retain quality staff are essential – particularly at the direct support level. All employers are experiencing significant increases in: benefit costs; workers' compensation costs; costs associated with the hiring and training process;, and costs associated with liability and other insurances. While staffing costs are an unavoidable cost driver and will increase over time on an individual staff member basis, the system (particularly providers) should identify and develop methods of delivering services and supports that are less staffing intensive.	12.a. The system should be firmly committed to the development and maintenance of adequate wages and benefits for workers providing direct support in the system. The viability and success of community supports is dependent, in part, on ensuring the stability of a well-trained, consistent staff. 12.b. Study the potential for minimizing staffing requirements through staff sharing between programs in close physical proximity (overnight staff in 24-hour programs). *See #4., above, for additional information.* 12.c. Develop additional residential models with less intensive staffing requirements such as congregate apartment living, ISO's and other live-in options. 12.d. Increase community inclusion activities, relying on natural supports when possible. With increased focus on community inclusion, it is important to keep in mind that individu-alized service planning doesn't necessarily translate into one-on-one service delivery. 12.e. Develop partnerships with technical schools, community colleges and the university system to establish internships and practica so students will learn about careers in community-based services to persons with disabilities and enter the field with increased knowledge and awareness of the requirements and expectations of the work. 12.f. Work with community colleges and the state university system to ensure professional curricula result in the acquisition of critical skills and competencies.

13. Administrative and programmatic redundancies • Considerable overlap and duplication exists between DHHS administrative and case management processes and systems and those required to be in place at the provider. • Certain financial and accounting practices are also redundant and may not be useful (such as 100% audits of programs rather than performing an audit of a randomly chosen sample of providers on a yearly basis or relying on the independent CPA audits required of all organizations.) • G&A costs (administrative overhead) are capped at an extremely cost-conscious level for community service providers. This severely limits any benefit to merging medium and large providers with the intent of minimizing administrative expenses. However, it may be possible for smaller organizations to reap financial benefits by partnering with other organizations to share selected administrative services.	13.a. Identify a group of service providers, state officials and primary/secondary consumers to study the existing service system in order to identify administrative and programmatic redundancies and service duplication across the system, particularly related to services provided by the State and community providers. Eliminate the redundancies or duplicative services whenever possible. The following approach (or one that is similar) may be used to approach this process: Step 1: Define what service functions exist across the entire State/provider complex. Step 2: Identify what activities are required to plan, implement, monitor and evaluate each of those service functions. Step 3: Define the roles and responsibilities that are required to accomplish the activities identified in Step 2. Step 4: Identify the areas of overlap and duplication across the State, providers (and others?) Step 5: Assess who can perform the task most effectively and efficiently. Step 6: Eliminate the duplication and/or overlap to better control increasing costs. 13.b. Create incentives to allow and promote provider partnering across functions such as billing, accounting, human resources, information services, health and safety, quality assurance, adult protective investigations, PCP coordination, and relief staffing.
14. Increases in technology requirements that are necessary to perform the essential functions of providing services and linking with the State system for billing, documentation, and reporting	14.a. Standardize software for billing, accounting, case management and reporting and make this available across the system. *This would allow the state to interact with providers in real time and be immediately aware of spending and/or savings as they occur. Currently, the state spending and budgetary implications are clarified upon audit, 4-6 months following the close of the fiscal year. The real time nature of an integrated system would improve planning and budgeting greatly at the state level.* 14.b. Allow all services (state and providers) to access the EIS system as users. *This would allow for greatly improved exchange of program information and minimize redundancies caused by parallel, but non-interacting systems.*
15. A lack of consistency exists in the quality of service delivery and support/training for state case managers and agency staff across the state. As long as the focus of regulations used to monitor services and hold programs and services accountable (providers and state services) are based on process rather than outcome, this lack of consistency in quality will continue.	15. Study the feasibility of changing the model of accountability to a focus that includes an emphasis on outcomes in addition to the current focus on process. *At this point in time, most of the regulations and standards (including ICF, the current Medicaid waiver, assisted living, and the stipulations of the consent decree) focus on process expectations rather than outcome expectations. Many of these regulations and standards are tied to statutory regulations so statutory change (or exceptions) would be required to make significant modifications. The advent of the DHHS EIS system, the use of the Quality of Life Survey and similar tools, archival and evaluative data from the PCP process, the indicators projects and the use of*

	comprehensive assessment are all promoting an increased focus on outcomes. This is a strong indicator of positive change in the system toward a focus on outcomes. *It is suggested that an outcome-based model should be the primary model for the future. While aspects of the process-based model must be retained to ensure accountability, they should not be dominant. Simply adding outcome-based models to the current process-oriented account-ability methods would increase overall costs significantly.*

III. C. Funding and Budgeting Process Drivers and Strategies

Cost Drivers	Potential Intervention Strategies
16. Loss of funds due to limited federal match A significant cost driver is the fact that the federal government has decreased its matching ratio to the State of Maine, thus requiring a higher level of state funding to draw down the same amount of federal money. This is a consistent practice across the US and it is anticipated that the trend to decrease the federal matching ratio may continue over the next few years due to diminished federal funding available for the human services.	Unsure – there may not be a successful intervention strategy for this cost driver other than negotiating with the federal government to maintain and expand federal support to states. 16. Advocate with the Maine Congressional delegation to expand federal relief to states (e.g., maintaining the Medicaid match ratio at the FY2003 level), particularly during this period of budget downturn.
17. Community support provider budget development and monitoring The current budget development process does not result in a useful, practical budget. The approach each year is characterized by widely changing models, varying expectations, extraordinarily limited timelines (e.g., for FY2005, the budget templates were forwarded to providers approximately three weeks prior to the time they were due and the accompanying instructions required another week to arrive.) The requirement of a zero balance budget on a program-by-program basis (as opposed to a full corporate budget or even a departmental budget) forces providers to create unrealistic budgets. Each program budget is treated as if it is simply an additive function of individual consumer budgets. While this is an ideal, it is rarely possible. Individual changes in a consumer's needs or in the PCP-driven program, coupled with the uncertainties of the political and legislative process require that flexibility is built into each individual program budget. This allows a corporate budget to portray a realistic zero balance, with allowances made between and among programs.	17.a. Allow budgets to be submitted as zero balance budgets on a department/organization basis (e.g., residential, day service, independent living departments) or as a deficit budget if that reflects the true reality of the service as delivered by that provider. *This action would allow providers to submit realistic budgets and allow the state to monitor expenditures in a consistent manner.* 17.b. Explore the possibility of transforming the entire system to a fee for service model relying on a consistent and standardized rate setting methodology based on consistent and well-communicated service definitions. *This action would allow for the use of a random audit function and improved monitoring of expenditures. It may also fit an outcome-based model of evaluation better than the current system. This would yield significant state and provider savings.* 17.c. Pay for services based on 1/12 monthly allocation of an approved annual budget, with quarterly reconciliation or fee-for-service monthly payment. *This would streamline the billing and accounting practices for both providers and the State of Maine and allow for fluctuations and changes in the budget created by evolving consumer needs and program or department changes. It would allow for increased efficiency while still meeting all accountability requirements.* 17.d. Consider implementing longer term state budget projections (5 years) to allow programs to plan for potential changes in revenue streams.

18. Lack of expertise and experience in business and accounting among people who plan, regulate and monitor the DHHS financial support of services to adults with mental retardation.	Considerable financial planning and many financial decisions are made either by or in concert with persons in the Resource Coordinator position at the DHHS regional level. If this position required financial acumen and experience, the costly confusion associated with the individual budgeting process would be minimized for both the State and providers.
19. The State is challenged in its ability to monitor budgets and expenditures on a real time basis For example – suppose an independent living program is approved to provide services that will result in reimbursement of $300,000. Over the course of the year, the services are provided at a level that results in a $200,000 draw down of funds at year end. The State accounting and financial monitoring system should operate in "real time" so the system is aware of actual expenditures. As it is now, the $100,000 difference is only identified following the audit process which is fully completed 5-6 months following the end of the fiscal year. The limited ability to monitor current finances in real time is a cost driver.	19.a. Identify standardized software for billing, accounting, case management and reporting and make this available across the system. *Interacting with providers in real time is essential. Please see 14.a. for further explanation.* 19.b. Ensure a system is in place in the payment system so the State automatically stops paying when individual program-based spending caps are reached.
20. Occupancy costs (vacancies) The protocol put into place during FY04 to address unplanned occupancies in residential programs may well result in increasing costs to the system. The current method of facilitating referrals is highly inefficient, relying on a funneling process controlled by one or two people in a region with one prospective consumer being referred at a time. This protocol threatens true partnership between the State and providers. Because of the limitations imposed by the current protocol, DHHS does not experience any urgency to address residential vacancies. The only urgency is experienced by providers and program staff who have up to 60 days to fill the program slot before a significant financial shortfall is experienced and the viability of the entire program is directly threatened.	20.a. Study the impact of the current policy on the viability and success of residential services that have been identified as essential to the good of the system and make revisions as necessary and appropriate. 20.b. In combination with 20.a., it will be important for a representative group of stakeholders to identify the future need for specific types of residential options. This may include the number of residential programs of a specific type and size per geographic location. ***It will be very important to include estimates of persons who currently live at home with a family member and who will have service needs in the future.***

III. D. Drivers and Strategies Associated with the Cost of Doing Business

Cost Drivers	Potential Intervention Strategies
21. Administrative overhead of state • Over a period of 8 years – 1995 to 2004 – there has been a 7% post inflation <u>total</u> increase in appropriations to community providers for direct support of consumers. During this same period, there has been a 31% increase in the number of people served in the system. There has been a corresponding post inflation increase of 83% in appropriations for DHHS (operating as BDS) regional office operations. • It is important that administrative costs of DHHS (totally and in support of adult MR/DD services) parallels the level of cost that is expected of community providers.	It has been reported to the working group that the regional system and its corollary programs and supports are possible because of Medicaid revenue from state-provided case management services. The development of the regional system was funded by a sharp increase in appropriations for regional office operations, while only a minimal post-inflation increase was received by the providers who deliver the primary support services. Some of the money that funds the administrative overhead of the state could have been invested into community services during this same period (not for administrative overhead, which is capped at a very modest level) for the improvement and expansion of consumer services and supports. While this references events in the past, it is also a current issue that should be studied more fully.
22. The State's response and approach to meeting the stipulations of the Community Consent Decree is a cost driver for services to consumers who are members of the protected class as well as for consumers who are not class members. The services described by the consent decree define the minimum level of services to members of the protected class. The decree also requires that the state should have "mechanisms of future compliance" in place that will guarantee to class members the services required by the decree, so that even after the federal court relinquishes active jurisdiction over the case, class members will continue to receive the level of services that are now legally mandated.	22.a. It is the opinion of this working group that all Maine citizens who meet the criteria for MR/DD services should receive services parallel to those described in the decree. *The service levels defined in the consent decree may have contributed to the development of a system that is more comprehensive and intensive than is required and/or desired by many consumers. Also, the framework of the consent decree may not be based on current best practice models or empirically validated service approaches that have been developed over the past decade. It is important, therefore, that the mechanisms of future compliance and the service system should be flexible so they can reflect this new level of understanding.* 22.b. The "mechanisms for future compliance" should be flexible in the definition of how the minimum level of service is defined and should be applied on an individual basis. This should allow for state-of-the-art individualized services, provide for accountability in the service delivery system, and create adequate guarantees of service for each person.
23. Housing and community living costs continue to escalate, regardless of type of residential option chosen Housing costs and all of the costs associated with maintaining a community-based life continue to rise on a statewide and national basis. This is true for group homes, individual homes,	23.a. Study the potential for ownership options for consumers that would transcend providers. 23.b. Increase the use of Section 8 and other HUD and Maine State Housing Authority options. 23.c. Enter into negotiations with the Social Security Administration to standardize benefit amounts

national basis. This is true for group homes, individual homes, apartments, any center-based day or vocational programs and services, and personal homes (for ISO, family-based and live-in options). Regardless of whether providers or families own or rent, purchased years ago or are new to the market – costs associated with living in the community will, in all likelihood, continue to increase. In some parts of the state, costs associated with housing have reached (or have surpassed) a critical level in terms of the balance between space costs and money that is available through Social Security or other sources to cover those expenses. Unfortunately, this is true in counties with the greatest populations – where a majority of DHHS services are delivered.	between people who participate in Waiver homes vs. those who participate in PNMI homes or independent living options. (More than $200 difference exists in monthly benefit paid to people living in a PNMI program). The current methodology to establish benefit levels is based on an outmoded set of assumptions in the Social Security Administration. 23.d. Promote the generation of income among consumers which can be used by them to partially or fully support housing costs and other living expenses. *Don't necessarily expect increasing costs of housing to be eliminated as an issue by seeking to engage more in ISO and live-in residential options. Housing costs are rising for everyone and will be reflected in the cost of the program, regardless of the type/location of the program and whether they are paid for directly or indirectly. This is a factor that must be built into any long-range planning effort where consumers are directly or indirectly responsible for supporting the shelter, food, utilities and other costs associated with living in the community.*

III. E. Miscellaneous Drivers and Strategies

Cost Drivers	Potential Intervention Strategies
24. Considerable inconsistency exists among legislators, State administrators and employees, providers and others regarding the degree to which the current fiscal crisis is a transient or long-term challenge. This inconsistency in point of view complicates the planning and decision-making processes and becomes a cost driver in the system.	If one believes the problem is transient – one set of strategies will be developed. If it is believed this is a state of affairs that will be encountered on a long-term, basis, then quite another set of strategies must be developed. The inconsistency in point of view is understandable, but some level of agreement must be reached to guide the development and selection of strategies to address the challenges. 24. Consider implementing longer term state budget projections (5 years) to allow programs to plan for potential changes in revenue streams. (see 17.d.)
25. Staff turnover Turnover in some provider organizations can be as high as 60% of the direct support staff. This is a consistent cost driver in the system. The DSP (Direct Support Professional) position is recognized by the United States Department of Labor as an apprenticable trade. This opens up opportunities to regulate the trade, increase wages and create more stability. Wages and benefits are not comparable to other jobs in the human service and health care industries in Maine that require a parallel skill set or level of training. This is true in the private sector as well as comparable jobs in municipal or state government. The lower wages and limited benefits contribute to the creation of a system that is always "on the edge" in terms of its ability to retain staff – during both good financial times and bad.	25.a. Raise wages via annual COLA. 25.b. The State of Maine has developed the Direct Support Professional training curriculum and has instituted a certification process. This is the first step toward an apprenticeship program and the possibility of broadly recognizing this trade as a valuable and worthwhile career. This recognition may be a first step to lessen the turnover problem. 25.c. Maine is participating in a model program sponsored by the U.S. Department of Labor, the Maine Department of Labor, the American Network of Community Options and Resources and the Maine Association for Community Service Providers that is designed to improve the recruitment, screening and selection of people to provide direct support. Projects such as this one should be encouraged and promoted. *Decreasing turnover lessens costs of recruitment, overtime, and training. Turnover also contributes to significant program and administrative inefficiencies, which are also significant cost drivers in the system. Addressing turnover would increase efficiency and effectiveness in the system, improve consumer successes, and control costs. While some of the money saved can be put back into the system, this would also free money to increase salaries – further reducing the potential for high turnover.* *It is important to note that significant increases in wages must be accompanied by lower staffing ratios and that these ratio changes must not effect the ability of consumers to be fully engaged in their communities (i.e., staffing ratios should not be lessened simply to provide higher wages if the quality of support and outcomes for consumers decline.). This requires a combination of creativity and flexibility that have been identified throughout this document.*

26. Transportation and coordination of transportation in a rural, geographically dispersed state Not only do direct costs associated with transportation continue to rise (vehicles, fuel, maintenance, staff time, and costs associated with personal auto insurance when staff use vehicles for business), but the costs associated with the coordination of transportation are increasing due to the cutbacks and more stringent requirements associated with the use and availability of public transportation (where that is available). In rural environments, transportation is always a primary cost driver.	26.a. DHHS and community providers should collaborate and coordinate with other people and programs who require transportation support in either rural, suburban or urban settings. This should not be limited to transportation programs that are designed to support people with disabilities or impairments. 26.b. Separate the application for and funding of transportation from a standardized rate model (or, develop a separate standardized rate setting structure for this specific factor). Separation will allow for improved monitoring and accountability of costs. While it is currently a separate budget line, it should also be funded separately in the future to allow increased precision in the budgeting and allocation process.
27. Living, working and operating a business in Maine is expensive in comparison to states of similar size, population, and stratification of socioeconomic level. This is particularly related to costs associated with mandated and optional employee benefits, insurances and other expenses that impact both non-profit and for-profit businesses.	While this is an influential factor – it is something that is quite resistant to change and certainly beyond the influence of this type of working group.
28. Life expectancy has increased overall – significantly so for persons with developmental disabilities The system of services was never set up or envisioned to support people as long as we are now – or will in the future. The entire system is retrofitted into the Medicaid system which, for the majority of participants, is designed as a time-limited service delivered during a transitional period or at the end of one's life.	28. Ensure that any type of service revision builds this fact into the planning process. Without this perspective, any financial gains in the short run will be lost over the long term.
29. People entering system or transitioning to a higher level of need. • Aging people living at home or in a community residence not in the system who have increasing needs and/or lack of support as they age, add cost. • Young adults transitioning from school to adult service often do not receive adequate services or training to promote success in this transition and minimize long-term costs.	29.a. Develop a plan specifically to address the needs of people entering the system: 1) Identify the number of people who are entering the system from school systems on an annual basis and estimate what their unique service needs will be. Create a collaborative effort between the Department of Education (through local school districts), the Department of Health and Human Services, the Department of Labor, and other interested/involved parties to develop, fund and implement a transitional plan to maximize the success of the transition. 2) Study the potential for establishing a specialized assessment team to work with adults who are entering the system for the first time or who require a significantly increased need for support. This team should be particularly focused on the unique needs of someone transitioning into the system at a later state in their development.

30. Ticket to Work – costly and not achieving what had been intended	A possible explanation: The Ticket to Work program was originally designed to address the vocational training and placement needs of persons on Social Security who were identified as having the potential for full inclusion in the competitive workforce within a defined timeframe. It was not designed to address needs of people who require substantial ongoing supports, nor was it designed to place people in part-time, accommodated positions. While it is a viable option for some people who are involved in Maine's MR/DD system, it will not be extremely useful for many participants in its current form.